DOCUMENT RESUME

ED 360 801 EC 302 383

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TITLE Supported Living: What's the Difference?
INSTITUTION Minnesota Univ., Minneapolis. Research and Training Center on Community Living.; Responsive Systems Associates, Lithonia, GA.
SPONS AGENCY National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.; Syracuse Univ., NY. Center on Human Policy.
PUB DATE 93
CONTRACT H133B80048
NOTE 20p.
PUB TYPE Viewpoints (Opinion/Position Papers, Essays, etc.) (120)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Adults; *Agency Role; Community Programs; *Developmental Disabilities; *Human Services; *Independent Living; *Individualized Programs; Place of Residence; *Social Agencies; Social Services
IDENTIFIERS *Supported Housing

ABSTRACT

This paper points out that the promise of supported living for individuals with developmental disabilities lies in its potential to deal creatively and individually with the complexities arising from the lives of many different individuals. The paper describes personal experiences of leaders in supported living agencies that enabled them to step outside the assumptions and practices that usually govern service providers. These experiences include being surprised to discover that people with disabilities are able to do things that experts have said they could not do, and recognizing similarities between oneself and people with disabilities which are much deeper than apparent differences. Supported living is defined by stating what it is not. Common assumptions made by the existing service system are identified and are accompanied by better assumptions. Common problems of people involved in supported living are discussed, such as poverty, loneliness and isolation, and complex relationships with staff. The paper concludes that community opportunities need to be created; collaborative relationships with family members need to be developed; and new ways to plan for people, deal with dangerous situations, find flexibility in funding, and supervise need to be created. The obligations of the supported living service provider to the person and to the person's friends and family are listed. (JDD)

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SUPPORTED LIVING: WHAT'S THE DIFFERENCE?

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1993

Prepared for
The Center on Human Policy
Syracuse University

Preparation of this paper was supported through a subcontract from The Center on Human Policy, Syracuse University for the Research and Training Center on Community Living. The Research and Training Center on Community Living is supported through Cooperative Agreement Number H133B80048 between the National Institute on Disability and Rehabilitation Research (NIDRR), Division of Special Education and Rehabilitative Services, U.S. Department of Education, and the University of Minnesota, Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily represent the official position of NIDRR.

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Supported Living: What's the Difference?*

John O'Brien

Supported living is a simple concept in danger of being complicated until its power to help people with developmental disabilities gets lost. Its simplicity is elegant.

a person with a disability

who requires long term, publicly funded, organized assistance

allies with an agency whose role is to arrange or provide

whatever assistance is necessary for the person to live

in a decent and secure home

of the person's own

Because people with developmental disabilities have different ideas about what a decent and secure home of their own would be like, different requirements for assistance, and differing abilities to communicate their preferences and needs, and because their ideas, requirements, and abilities change as they grow and develop, the promise of supported living lies in its potential to deal creatively with the complexities arising from the lives of many different individuals. Supported living focuses at the scale of individual lives, where there is the best chance of understanding the problems and possibilities in each person's situation: many people over extended time equals much variety in living and support arrangements. Increasing variety challenges common assumptions and structures for management, which typically aim to reduce variety.

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* © 1993, Responsive Systems Associates, Inc. All rights reserved. This paper is based on a two day retreat with California leaders in the development of supported living convened by Allen, Shea & Associates in January 1993, meetings with the staff and the board of Jay Nolen Services, Los Angeles, CA , and a half day meeting with members of Oregon's Supported Living Network in February 1993. Thanks to Charles Galloway, Connie Lyle O'Brien, Jack Pealer, Pat Puckett, Connie Saverino, and Doug Watson for their comments on an earlier draft.

Preparation of this paper was supported through a subcontract from The Center on Human Policy, Syracuse University for the Research & Training Center on Community Living. The Research & Training Center on Community Living is supported through a cooperative agreement (Number H133B80048) between the National Institute on Disability & Rehabilitation Research (NIDRR) and the University of Minnesota Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily represent the official position of NIDRR.

The capacity to generate a variety of types of assistance is the essence of supported living. Potentially destructive complications arise from at least two sources:

- Supported living expresses a fundamentally different relationship to people with developmental disabilities than most other approaches to service do: instead of controlling people with disabilities in order to fix (train, habilitate, rehabilitate, treat) them, supported living workers seek to cooperate with people with disabilities in order to develop the assistance they need to get on with their own lives. This contrast creates dissonance for service workers and managers accustomed to services based on control; the least difficult resolution of the dissonance is to practice the habits of control and call it support.

- Supported living is developing in a time when scarcity, lack of public consensus on the management of scarcity, and rapidly escalating complexity and uncertainty haunt public managers at every level. Decades of rising expenditures on services to people with developmental disabilities (mostly present or former institution residents) have accumulated frighteningly large waiting lists (mostly of people who have been cared for by their families) for costly services. This demand has grown as hundreds of pages of statutory, regulatory, and procedural commitments have accumulated. This situation frightens many public managers into a futile search for greater and greater administrative control. Supported living, even more than other innovations, needs slack to develop and can never be uniform and predictable in the way that services based on standardized control of clients can be. This makes supported living an attractive but threatening anomaly. It's attractiveness tempts administrators to load it down with untested promises (for example, supported living will be much cheaper because every participant will be required to make extensive use of 'natural support,' which is free to the developmental service system). Its threat tempts administrators to hedge it in with increasingly detailed requirements.

The challenges come from these complications: Can those who want to provide supported living step outside of the habits of thought and practice that govern most existing services to people with developmental disabilities? And, can those who want to sponsor supported living create more effective ways to manage public resources on behalf of people with developmental disabilities?

These notes attempt to communicate some of what is different about supported living as it emerges in the sustained work of a small number of agencies whose staff have been learning the hard and happy lessons of providing personalized assistance since before anyone coined the term "supported living" or established a funding source by that name. Focus on the differences that supported living wants to amplify offers a base from which to negotiate the challenges of distinguishing supported living from other forms of service and evolving effective means of public accountability.

Understanding Supported Living Depends On Personal Experience

Effectively providing supported living calls for a commitment to understanding the work from two perspectives: the perspective of unique individuals who have developmental disabilities; and the larger, social perspective of people with developmental disabilities as a devalued group. These perspectives develop from reflection on personal experiences with people with disabilities. How well you understand supported living depends on where you stand in relationship to people with developmental disabilities. If you *stand over* people, assuming that you know best and that people with disabilities will be better off if they do what you say, you will miss the point of supported living. If you *stand away* from people with developmental disabilities, assuming that they are dangerous, shameful, pitiful, or unacceptable, you will miss the point of supported living. If you see no need to reconsider your own assumptions about and behavior toward people with developmental disabilities, you will miss the point of supported living. Only when you *stand with* people with developmental disabilities, recognizing their common humanity, honoring their desires to make a life for themselves, and struggling with them to create new opportunities, can you begin to understand supported living.

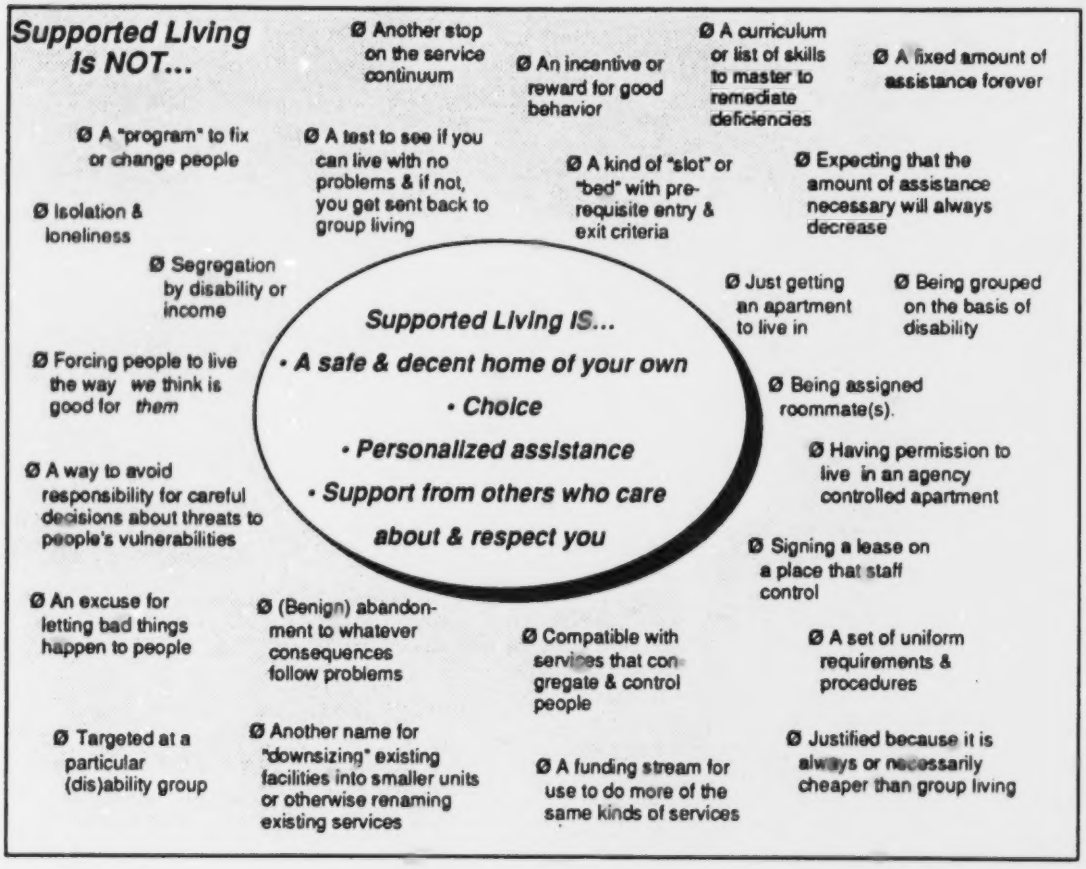
A group of leaders in agencies pioneering supported living identified some of the experiences that have enabled them to step outside the assumptions and practices that usually govern service providers. It will be easier to understand what is different about supportive living if you can draw on personal experiences like those described in the following table.

Experience	*Example*
• Being surprised to discover that people with disabilities are able to do things that experts have told you are impossible for them to do (especially when you believed the experts).	– Running a marathon with people who weren't supposed to be capable of running a mile. – Listening to someone for the first time through augmented or facilitated communication – Learning to teach someone a complex assembly task.
• Sensing injustice and wanting to act when people underestimate or exclude people you know with disabilities.	– Seeing people in an institution and knowing it was wrong for them to have to be there – Deciding to break rules that required demeaning treatment of people with disabilities – Seeing kids go from an integrated preschool to a segregated kindergarten and deciding to work for change in the schools – Being outraged to discover how many people with disabilities have been sterilized.
• Feeling confusion, loss, and anger when others exclude a person you know because they see a disability as the most important thing about someone you know as a friend.	– Missing a childhood friend institutionalized after a car accident and continuing to wonder why it had to happen that way. – Wondering how other people could just assume that a neighbor with a severe disability belonged in segregated settings. –Feeling very uncomfortable with the hierarchy of status imposed on "staff" and "clients." Thinking that things like separate staff toilets and rules and procedures about how "we" should interact with "them" seem like apartheid.
• Sharing personal time and activities as an equal with people with disabilities –not being a caregiver or a supervisor or a trainer.	–Going camping with a person with a severe disability and discovering new ways to just be with her. – Watching late movies and eating popcorn with people (against the rules of the facility). – Spending time with a person with a severe disability who is dying well. – Finding yourself helped and supported through a hard time by a person who was supposed to be a "client".

• Purposely choosing to change your usual role and learning from the change.	– Being an active member of a support circle for someone who is neither a relative nor a client. – Providing personal assistance to someone instead of supervising their program. – Being part of the creation of an innovative service either as part of a planned effort or because no one knew what to do for a particular person and you decided to do whatever it took to make things work for that person.
• Discovering big differences in life experiences between oneself and some people with disabilities.	– Being reminded over and over how little money people get to keep. – Having someone you have known for 15 years continue to seek reassurance that you are their friend. –Studying the history of services to people with developmental disabilities and the theory of normalization and finding a frame of reference for understanding the systematic pattern of negative experiences imposed on socially devalued people.
• Recognizing similarities between oneself and people with disabilities which are much deeper than apparent differences.	– Discovering that a group of people with developmental disabilities share your personal experience of surviving childhood abuse. – Feeling the continuity between a family tradition of work for social justice and the personal struggles of people with developmental disabilities. – Thinking over and over again about a teacher's comment: "There is less difference between any ordinary person and a person with a profound disability than there is between any person and their potential."
• Enjoying the results of the challenges and conflicts that come from embracing diversity.	– Getting an entirely different approach to a difficult personal problem from someone whose culture and experiences give them a completely different way to look at the world. – Becoming best friends with someone who is as different from you as can be.

A Negative Way Toward Definition

It is helpful to define the edges of supported living by saying as clearly as possible what it is not. This diagram summarizes a number of the misunderstandings of supported living encountered by a number of leaders in providing supported living.


Supported Living Is NOT...
Ø Another stop on the service continuum
Ø An incentive or reward for good behavior
Ø A curriculum or list of skills to master to remediate deficiencies
Ø A fixed amount of assistance forever
Ø A "program" to fix or change people
Ø A test to see if you can live with no problems & if not, you get sent back to group living
Ø A kind of "slot" or "bed" with pre-requisite entry & exit criteria
Ø Expecting that the amount of assistance necessary will always decrease
Ø Isolation & loneliness
Ø Segregation by disability or income
Ø Just getting an apartment to live in
Ø Being grouped on the basis of disability
Supported Living IS...
• A safe & decent home of your own
• Choice
• Personalized assistance
• Support from others who care about & respect you
Ø Forcing people to live the way we think is good for them
Ø Being assigned roommate(s).
Ø Having permission to live in an agency controlled apartment
Ø A way to avoid responsibility for careful decisions about threats to people's vulnerabilities
Ø Signing a lease on a place that staff control
Ø An excuse for letting bad things happen to people
Ø (Benign) abandonment to whatever consequences follow problems
Ø Compatible with services that congregate & control people
Ø A set of uniform requirements & procedures
Ø Targeted at a particular (dis)ability group
Ø Another name for "downsizing" existing facilities into smaller units or otherwise renaming existing services
Ø A funding stream for use to do more of the same kinds of services
Ø Justified because it is always or necessarily cheaper than group living

Notice that the misunderstandings express several contrasting themes.

Common Assumption	*Better Assumption*
• The existing service system just needs improvement through the addition of another service element or minor reforms (e.g., making service settings smaller)	• Supported living is compatible with the goals of public policy for people with developmental disabilities (e.g., concern for individualization, integration, and choice). But it is a fundamentally different way to work toward those goals. It challenges, and overturns, the logic of any service continuum and most current forms of regulation.
• People with developmental disabilities need professional people to define their problems, prescribe solutions, and exert control to insure compliance with their recommendations.	• People with developmental disabilities need allies who will… …help them define what matters to them and …help them develop the system of personal assistance necessary for them to pursue what matters to them. …help them resist intrusive and disrespectful regulatory and service practices
• People with developmental disabilities should either be in a program (under staff control) or on their own (with minimal or no assistance).	• People with developmental disabilities can be in charge of their own lives *and* get the assistance they need to live in safety and dignity.

• Service providers are primarily responsible to insulate people from risks. Often this will mean controlling a person's access to opportunities and activities.	• Service providers are responsible to assist people to deal constructively with their vulnerabilities. Sometimes this means sticking with people through very difficult and confusing experiences and sometimes it means working hard to negotiate a safer situation with a person.
• It doesn't really matter who controls the home of a person with developmental disabilities.	• When given the opportunity, many more people with developmental disabilities than anyone ever thought want the assistance necessary to be in control of their own homes.
• The kind and amount of assistance a person with a developmental disability will need can be predicted and reliably planned in advance.	• The kind and amount of assistance a person needs will vary up and down, depending on changing interests, needs, and social resources. Flexibility and creativity are the hallmarks of supported living.
• Supported living can be specified and controlled from above, through bureaucratic authority: standards, regulations, and rate setting.	• Providers must learn about supported living through active learning along with the people they assist. Regulation according to uniform standards suppresses the kind of action learning that is necessary for supports to develop.

Supported Living Means Choosing New Problems

One of the biggest challenges to established providers who want to convert their services to supported living lies in the unfamiliarity of many of the problems they will encounter. Existing services have evolved as a set of habitual solutions to common problems, forming a kind of culture. Serious engagement with supported living raises the problems beneath these habitual solutions into uncomfortable awareness and calls for new solutions.

People involved in the work of supported living have identifies the complex mix of problems identified in the following paragraphs.

Poverty

As people move into their own places and rely on SSI, Food Stamps, and rent subsidies for their living expenses, the reality of their material poverty becomes more apparent. They, their families and friends, and staff become more aware of the quality of housing, transportation, and health care available to poor people. The issues arising from people's poverty demand substantial problem solving effort.

Loneliness & Isolation

For some people, moving away from a congregate setting increases loneliness. With adequate opportunities and help, a person can respond to loneliness as a motive to develop connections to other people and activities. If staff and important others ignore or interpret the person's loneliness as unavoidable, the person may well slip from a transitional state of loneliness into long term isolation.

Complex Relationships With Staff

People who enjoy their relationship with paid staff may express little interest in expanding their personal connections, preferring instead to hang out at home with staff. Staff with positive relationships need to be particularly conscious of the benefits of a growing social network and active in offering people opportunities to try new things and meet new people.

Successful matching of people with disabilities and paid assistants results in a positive, personal relationship. Some people with disabilities will come to see their assistants –particularly paid roommates– as friends. This can create problems when the assistant performs necessary tasks poorly, especially when other

staff are concerned about performance problems that the person supported is willing to overlook because of feelings of friendship.

Reconsideration of Basic Ideas & Usual Practices

Staff must re-think the principles which have guided practice in agency controlled settings. Some agencies have organized teaching activities to shape independent performance to a 'normal' standard: their goal has been to move the person from disability (doing different things differently from 'normal' people) to normalcy (doing the same things the same way as 'normal' people do them). Some agencies have standards for physical environments that are incompatible with the kinds of places and furnishings usually available to people who are just starting out in their own homes. Assuring that people have safe and decent accommodation and providing effective ways for people to develop relevant skills are important contributions of supported living. But the ways these contributions are made and the standards for judging performance shift when services respect and work to increase people's autonomy.

Instead of referring to standard procedures for solutions to problems, supported living workers learn to refer to their understanding of the person's life. What to do about a person whose refrigerator isn't clean depends on the person, the expectations of other important people like landlord or roommates, and the kind of relationship the person has with the worker and the agency. Understanding context is essential to good problem solving.

Some agencies have grown accustomed to thinking about their obligations to their clients primarily in terms of meeting regulatory requirements and avoiding legal liability. In our litigious society, this impersonal and defensive way of dealing with people is reinforced by insurance companies and some regulators. As an agency shifts from providing a total program to clients in an agency facility to supporting people in their own homes the nature of the agency's responsibility shifts in uncertain ways. It becomes less clear where the person's responsibility for choice begins and the agency's sole responsibility leaves off. Agency preoccupation with avoiding liability blocks the development of responsible ways to strike an individualized balance between personal vulnerability and individual autonomy.

Creating Community Opportunities

Much of what people with developmental disabilities need most, they need from other members of their communities. Because historical patterns of discrimination have excluded people with developmental disabilities from many aspects of community life, supported living workers have to be active in developing community opportunities with the people they assist. If supported living workers are passive, exclusion and isolation will continue. Because many services have responded to people's exclusion by attempting to simulate community life within services, workers will find themselves dealing with many situations where the presence and active involvement of a person with a developmental disability is a new, and possibly a strange, idea.

Some community members may believe that service agencies exist to contain and control people with developmental disabilities. Re-positioning the agency as a support to people may call for education, negotiation, and perhaps conflict. Conflict can be threatening if it involves politicians, the media, or the police.

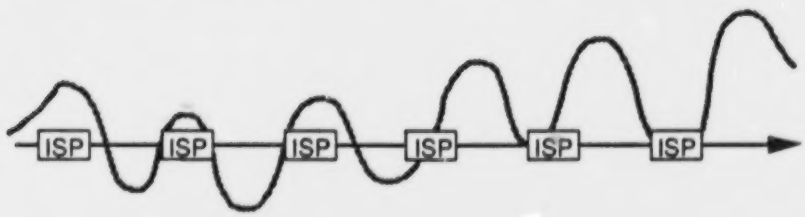
Collaborative Relationships With Family Members

Some family members believe that services that control people with developmental disabilities are necessary for their safety and that choice would be dangerous. Some family members believe that congregating people with developmental disabilities together is necessary to prevent isolation and loneliness. Some family members believe that professionally prescribed treatments are the most important things for people with developmental disabilities. Because supported living is based on beliefs which may be different from those held by family members, supported living workers must become skillful at listening to family members' concerns, negotiating agreements with them, and, sometimes, balancing the concerns of family members with the choices of competent people with developmental disabilities. Negotiations with some family members will be more difficult because they have received, and followed, contradictory advice from professionals committed to controlling people with developmental disabilities.

New Ways to Plan For People

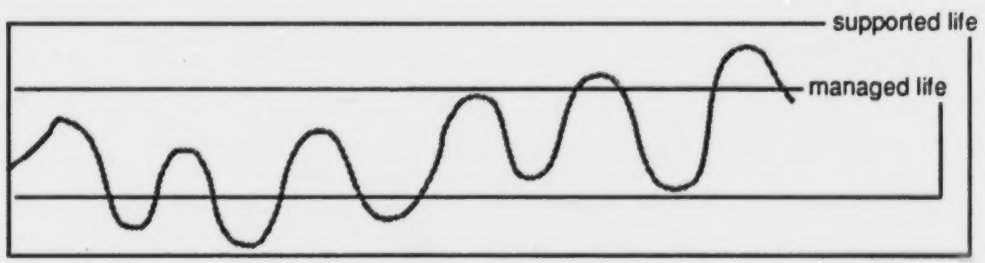
The service system plans for people in a linear, rational way. Annual objectives and regular periodic reviews are supposed to control the amount, direction, and

means of assistance a person receives. This assumption is built into the regulation and review systems. But people's real lives change differently. Needs for more or less support or the discovery of a new area of need or interest doesn't follow an orderly pattern. Supported living agencies end up working around and amending formal individual plans much more than implementing them.



New Ways To Deal With Dangerous Situations

Some people with developmental disabilities may be dangerous to themselves or to other people. The basic image of supported living –keeping up with changing needs for assistance in ways that put the person's choices first– may need to give way to managing a person's life: taking purposeful action to limit the persons choices. It is very challenging to deal with both these kinds of assistance but, if an agency chooses not to do so, some people –for example people who get into conflict with the law or people whose judgment is dangerously poor– will lose their place in their community.



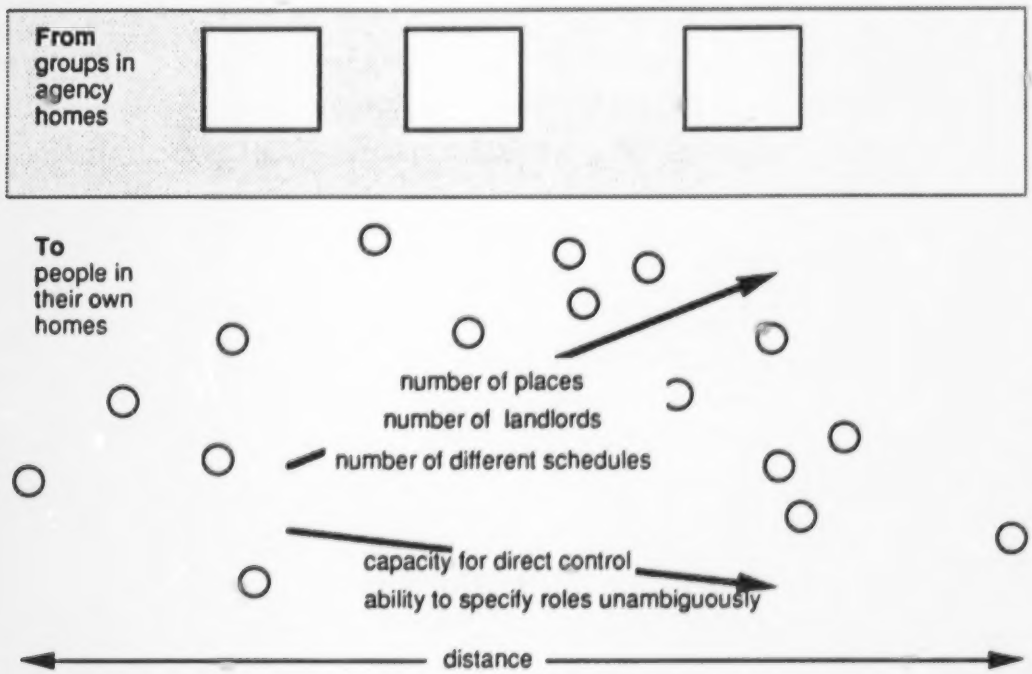
This problem is compounded when service system managers define supported living primarily as a response to people whose needs are extremely challenging to understand and meet. Narrowing the availability of supported living in this way not only discriminates against the many people with developmental disabilities now contained by group living arrangements, it distorts the development of supportive living agencies by multiplying the number of very complex situations they must deal with.

New Means to Find Flexibility in Funding

Individualized funding may reduce the slack an agency can use to respond flexibly to changing needs. Administrators who have learned creative ways to save and shift funds within group home budgets to allow for innovation or exceptional circumstances have less room to maneuver as support funds are controlled by person/hour of assistance.

New Forms of Supervision

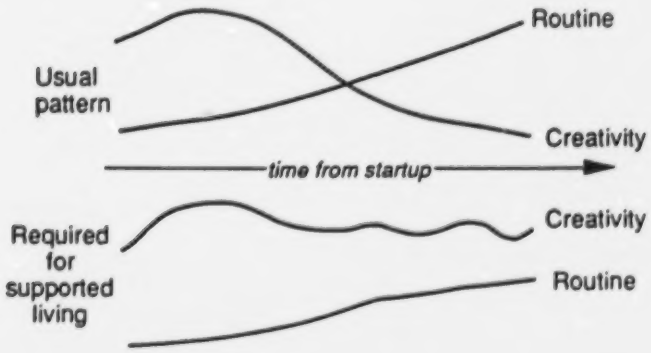
As people move into their own homes, direct, "eyes on" supervision of front line staff is virtually impossible. Staff must become much more autonomous in managing their schedules and in making decisions about people's well being and the best uses of agency time. In order to sustain effective alliances, all staff have to learn to make judgments consistent with agency values. Every worker will deal with community members. Some workers find this much expanded role challenging and interesting; others find it a greater responsibility than they want to manage. Managers have to learn to be effective consultants in problem solving and effective mediators in complex relationships. The agency must develop ways to insure that staff don't feel isolated and unsupported, and these must be thoughtfully created so that staff don't feel distrusted or manipulated.



The Need For Sustained Creativity

Typically, agencies value stability in residential arrangements. The need for creative effort seems highest at first, as the agency learns a new way of serving people. Creativity then drops off as people settle in to routine expectations and practices. Once the service model is standardized it can be replicated with little added effort. Supported living requires a much longer period of creative activity. New ways to relate to people with developmental disabilities and their families and friends take sustained creative effort. Effective routines develop around many tasks, such as helping people locate housing and dealing with people's physicians and dentists, but agency leaders need to channel the energy freed by these routines into efforts to increase the responsiveness and flexibility of the agency. Developing new opportunities in the housing market and in neighborhoods takes sustained creative effort. Responding to changing interests and needs in a flexible and economical way takes sustained creative effort. Responding to changing external requirements in ways that preserve agency mission and values takes sustained creative effort. Renewal of mission and en-

couragement of active problem finding define key leadership tasks in a supported living agency.



As supported living agencies face these problems and consciously develop and share solutions they will develop a new culture to give meaning and direction to their work. Given the difference between supported living and most other forms of service, it is especially important for supported living workers to maintain a strong network of personal connections to others doing the same work in other places.

The Obligations of Supported Living

In many forms of service to people with developmental disabilities, the service provider's primary obligation is to provide contracted services to eligible clients. If the provider lives up to applicable regulations, any failures belong to the client. Supported living turns this common situation inside out. Supported living workers recognize that people with developmental disabilities need committed, capable allies if they are going to overcome the barriers imposed by widespread prejudice and discrimination. Becoming someone's ally doesn't necessarily mean becoming their close friend or endorsing everything they do or want. It means being willing to be involved in a constructive way in helping a person discover and move toward a desirable personal future.

One way to clarify this essential relationship is to say what obligations the providers of supportive living should accept to the person they assist and their families and friends.

Obligations to the Person

We acknowledge that in order to assist you effectively we must earn your trust and the distinction of being your ally by...

...treating you with respect and listening carefully to you so that we can keep getting to know you better

... learning with you about your interests and preferences and identifying the kind of home that will offer you a safe, decent base for your participation in community life

...learning with you about the kind, amount, and style of assistance you need to live successfully in your home and your community

...working with you, and your family and friends, to establish the home life you desire and the assistance you need

...recognizing the social, financial, and personal barriers to the kind of home life you want and assisting you to work to overcome them

...understanding the vulnerabilities to your well being that result from your disability and your personal history and carefully negotiating safeguards with you that balance risk and safety in a responsible way

...being flexible and creative with all the resources available to us to respond as your interests, preferences, and needs change

...keeping responsibilities clear so that, in every area in which we work together, you and we know what you will contribute, what your family and friends will contribute, and what assistance and support we will contribute

...minimizing our intrusion in your life by periodically checking to make sure we are not doing unnecessary things or doing necessary things in intrusive ways

...sticking with you in difficult times

...learning from our mistakes

...following through on our commitments to you and not making promises to you that we can't keep

We recognize that social, legal, and service developments open many new possibilities for people with developmental disabilities and we accept responsibility to...

... provide you with information

...invite and encourage you to try new experiences

...invite and encourage you to widen your circle of friends and contacts

...hold high expectations for the quality of your life as a full citizen and community member

...stretch our own awareness of possibilities by actively seeking contacts with people involved in building up our communities and with people who are developing more effective and practical ways to assist people with disabilities

We know that you could find yourself in conflict with others: neighbors, landlords, other service providers, or the law. In these conflicts we recognize our responsibility...

...to be on your side, in the sense that we will assist you to achieve the best resolution of the conflict possible in the circumstances

...to assist you to understand the conflict and to consider alternatives for its resolution

...to assist other parties to the conflict to understand your position

...to consider adjusting kind or extent of assistance we offer you if that adjustment will help to achieve a satisfactory resolution of the conflict

We realize that you may disagree with us or be dissatisfied with our assistance to you and we accept responsibility to...

...negotiate openly with you in search of mutually satisfying outcomes

...try new ways to assist you and then check to see if the new approach has good results

...work hard to understand your communications about the adequacy and acceptability of assistance, especially when you can express yourself better through your behavior than in words

...assist you to explore other sources of assistance if you want to do that

We recognize that you might find close friends among our workers and, while we neither expect or require this kind of relationship, we gladly accept the potential difficulties that this might involve.

Obligations to the Person's Friends and Family

We acknowledge your importance to the person we assist. We want to invite and encourage your active support for a positive future for the person we assist; we do not in any way seek to replace you in the person's life.

We recognize that you may disagree with us or be dissatisfied with the assistance we provide, we accept responsibility to...

...respond to your concerns about the person's safety and well being

...negotiate openly with you in search of mutually satisfying outcomes

We realize that you and the person we assist may have different, perhaps even conflicting, ideas about what is possible and desirable for the person; in the event of these differences we agree...

...to uphold the importance of mutually respectful relationships among family members

...to assist you to negotiate a satisfactory resolution to the conflict, if our help is acceptable to you and to the person we assist

...if the conflict is serious and you cannot resolve it, we will maintain respectful contact with all parties but honor the choice of the person we assist.

These obligations make plain an uncomfortable fact at the heart of supported living: to assist people with developmental disabilities in this way is to become vulnerable to them, to their families, and to their communities. Our success depends more on inviting and assisting people with disabilities and community members to do what we cannot do: create satisfying lives and fulfilling community relationships.